ANNUAL REPORT

TEENAGE AND YOUNG ADULT SOUTH WEST

CANCER SERVICE

January – December 2017

Version: *1.0 Final*
Date: *28.09.2018*

CONTENTS

Definitions

Bristol Haematology & Oncology Centre	BHOC	Principle Treatment Centre	PTC
Bristol Royal Hospital for Children	BRHC	Site Specific Team	SiSp
Clinical Nurse Specialist	CNS	South West	SW
Psychology Health Services	PHS	SW Integrated Multi-disciplinary Management System	SWIMMS
Integrated Assessment Map	IAM	Teenage & Young Adult	TYA
Multi-Disciplinary advisory Team	MDaT	University Hospitals Bristol NHS Foundation Trust	UHB
Multi-Disciplinary Team	MDT	Young People	YP

SUMMARY

1.1 Key Achievements

- **2017 REACH Rate 96.15%** - The Teenage & Young Adult (TYA) service across the South West (SW) have 'Reached' 96.15% of all Young People (YP) captured on the cancer registry diagnosed between 16 and 24yrs of age (see section 10.3).

- Continued capital and support from, and close collaboration with, Teenage Cancer Trust to further develop resources in the designated hospitals within the TYA SW network.

- In line with the service objectives for 2016, the service has consolidated and maintained the networked model of care. This has been supplemented with the additional investment increase for the TYA Clinical Nurse Specialist (CNS) workforce with all posts appointed to 2017 (6.5wte posts).

- The regional service has actively promoted peer and social activities for YP both at the Principle Treatment Centre (PTC) and equally in each of the designated hospitals.

- The TYA Integrated Assessment Map (IAM) Portal Project was completed at the end of March 2017. Following the appointment of a national implementation manager in April, a roll out plan to implement the IAM portal across the UK by Teenage Cancer Trust in partnership with Macmillan Cancer Support, Sitekit and University Hospitals Bristol NHS Foundation Trust (UHB) is underway. The IAM Portal Project team won a Macmillan Innovation award for this work in November 2017.

- Reiki therapy and music therapy were added to the complementary therapy on offer in Area 61 Teenage Cancer Trust Unit in Bristol. Reiki provision is funded by Sam Buxton Healing Trust and music therapy by the Grand Appeal. It is available to children, teenagers, young adults and their networkers.

- The Teenage Cancer Trust CNS team were showcased by the Teenage Cancer Trust during the Royal Albert Hall Concerts in March 2017 – see Teenage Cancer Trust CNSs.

1.2 Key Challenges

- TYA pathways – there are various pathways for TYA patients across the region dependant on age and treatment location. Work continues in order to ensure shared engagement in the development of pathways, service standards, and quality and development initiatives in 2018.

- Transition – age criteria for admission to paediatric services differ across the network placing significant challenges for transition and management of patients aged 16-17yrs. Work to address this continues locally at each designated hospital and regionally for patients newly diagnosed, still on treatment, and in disease surveillance within this age group.

- Clinical trials - there remains a specific concern about the availability of, and access to clinical trials for TYA patients. The recently published ‘Achieving World Class Cancer Outcomes’ report includes a specific target for recruitment of 50% of TYA to clinical trials by 2025.

- Lack of clarity over commissioning arrangements for the whole pathways of care and the current financial climate, both in the NHS and third sector, are impacting service development initiatives. This specifically relates to ongoing funding of posts.

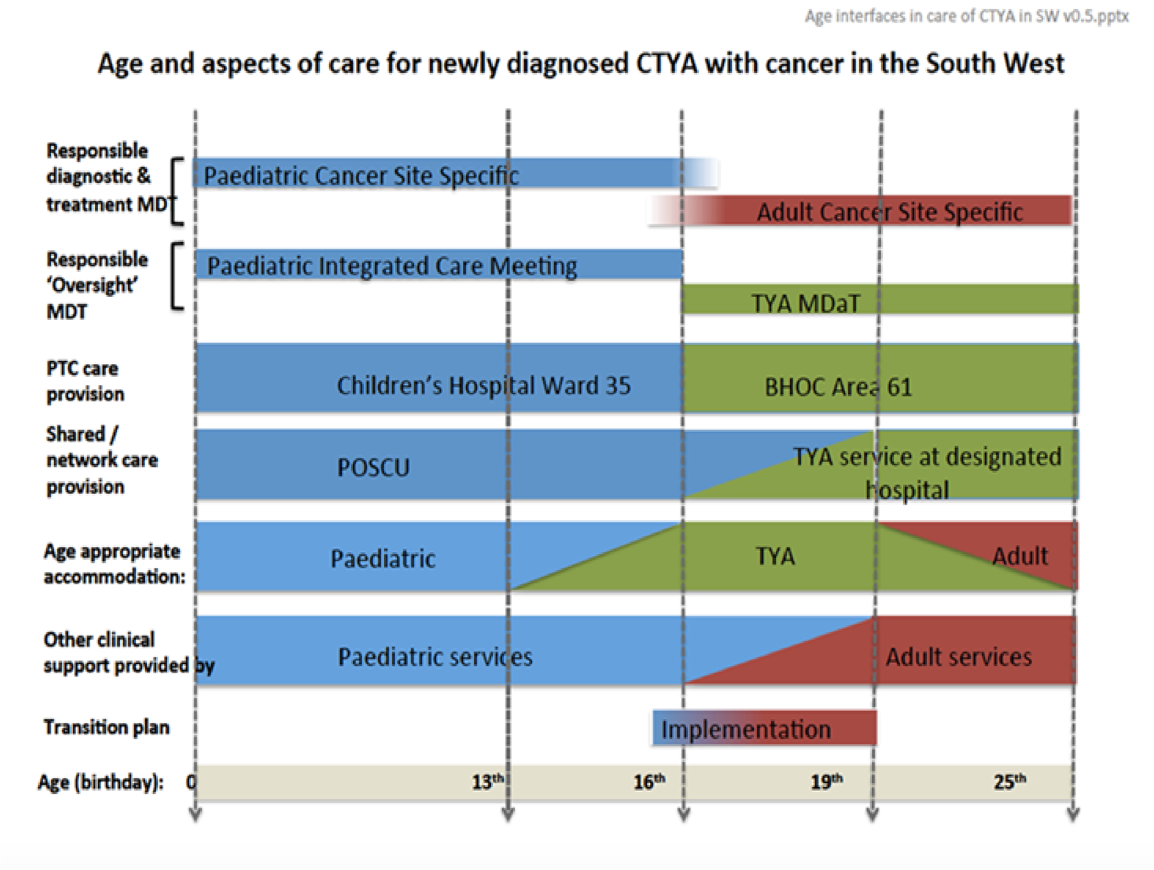
2. SERVICE DESCRIPTION

2.1 Population served

UHB (working in partnership with North Bristol NHS Trust) has been the designated PTC for TYA with cancer in the SW of England, a population of almost 5 million, since 2011. The PTC oversees the delivery of specialist malignant haematology and oncology care along with the provision of emotional, social and practical support to YP diagnosed with cancer.

A review of the lower age threshold for referral to the TYA service was conducted in collaboration with the childhood cancer service in 2016. This considered the complexity of the age interface in relation to: Multi-Disciplinary Team (MDT) discussion; provision of in-patient care at the PTC; provision of paediatric shared care and TYA designation across the region; the availability of age appropriate accommodation; and the provision of support from either paediatric or adult services. Variability exists in the policies about the upper age limits for paediatric care across hospitals involved in the network.

This is illustrated below:



The implications of this decision for the service has been that:

- all YP newly diagnosed with cancer from the 16th birthday to before the 25th birthday must be referred to the TYA Multi-Disciplinary advisory Team (MDaT) whether or not they are under paediatric or adult site specific cancer care.
- all children and YP newly diagnosed with cancer before the 16th birthday should be referred to the paediatric oncology/haematology service.
- YP newly diagnosed with cancer from the 16th birthday and before the 18th birthday may be referred either to paediatric or adult cancer services. Referral to paediatric services at this age may still be appropriate in relation to the nature of the diagnosis, the preference of the young person and his/her family; and his/her developmental status. Before making this decision, however, due consideration should be given to how shared care can be delivered, the need for a transition plan, and the possibility of requiring subsequent transfer to adult services.
- YP newly diagnosed with cancer from the 18th birthday should be referred to adult Site Specific Team (SiSp) cancer services.
- all children and YP who were originally diagnosed with cancer prior to the 16th birthday but who transit their 16th birthday whilst still on treatment, should be referred to the TYA MDaT whether or not they remain under paediatric care.

2.2 Background to the service and its model of care

The NHS England Standard Contract for TYA with cancer (B17/S/a) reflects previously published national guidance (NICE IOG 2005) and states that YP aged 16-18 years (i.e. to 19th birthday) should be referred to a TYA PTC for treatment in age appropriate facilities and that young adults aged between 19 and 24 (i.e. before 25th birthday) should be offered the opportunity to receive treatment at a PTC in age appropriate facilities. However, when the TYA service was first commissioned in the SW, a devolved network model of care was agreed with the Specialised Commissioners.

For geographical reasons, and in line with a long standing and well-established regional ‘shared care’ network in paediatric oncology in the same region, it was agreed that a regional network for TYA care would be established linking the PTC in Bristol with 6 designated hospitals offering TYA services across the SW.

They are:

1. Gloucestershire NHS Foundation NHS Trust
2. Royal United Hospitals Bath NHS Foundation Trust
3. Taunton & Somerset NHS Foundation Trust
4. Royal Devon & Exeter NHS Foundation Trust
5. Plymouth Hospitals NHS Trust
6. Royal Cornwall Hospitals NHS Trust

The rationale for this decision was to ensure that all YP were able, whenever possible and appropriate, to access treatment locally.

In order to support this arrangement, all patients were offered access to a dedicated Teenage Cancer Trust CNS (partnership funding between the NHS and Teenage Cancer Trust) and by a TYA Lead Clinician in each of the designated hospitals.

2.3 Facilities

There are two areas for the care of YP with cancer in the PTC at UHB, Apollo Ward in the Bristol Royal Hospital for Children (BRHC), and Area 61, a newly built TYA Unit for YP in the Bristol Haematology & Oncology Centre (BHOC).

Apollo Ward, caring for YP aged 11-16, is a 14-bedded ward consisting of ten single en-suite bedrooms and a four-bedded bay. Four beds in Apollo Ward directly support YP with cancer. There is active collaboration between Apollo Ward and Area 61.

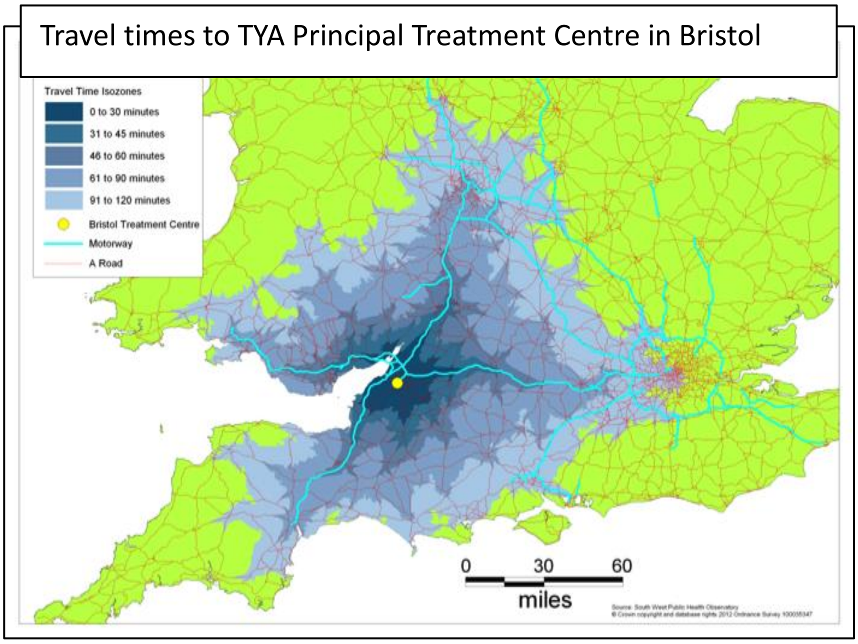
Area 61 was funded and developed in partnership with the Teenage Cancer Trust. The Unit opened in 2014 and provides care, treatment and consultation for YP with cancer aged from 16 to 24 years. It is built over two floors with one floor dedicated to in-patients featuring five en-suite rooms; a social area equipped with gaming and entertainment equipment and a kitchen and dining space; quiet room; treatment room; and a wellbeing room. The other floor is for day patients featuring three treatment 'pods'; three consulting rooms; social space; waiting area and a staff office.

Age specific facilities have been/are being established in many of the designated network hospitals, with Teenage Cancer Trust support. These developments are summarised in Figure 2.

2.4 The Network Model of Care

In the past, the development of TYA cancer services in the UK has benefitted from a model of centralised care that supported the development of clinical expertise and the provision of age appropriate accommodation. From the outset, this was not considered the optimal model for the SW, partly because of the geographical characteristics of the region, with long travel times for many patients to the PTC in Bristol (Figure 3) and partly because it was felt that it should be possible to deliver high quality care for many YP using the resources and skills available at the designated hospitals, closer to their home, with the support of the PTC.

In order to achieve this, the specialised commissioners and Teenage Cancer Trust have invested in a number of Teenage Cancer Trust CNSs linked both to the PTC and to the designated hospitals.


Travel times to TYA Principal Treatment Centre in Bristol

Source: South West Public Health Observatory
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Figure 3. This illustrates the challenge for delivering centralised care in the SW, particularly for patients in Devon & Cornwall, many of whom reside > 2hours travel time away from Bristol. (The green areas indicate one way travel times >120 minutes)

The network approach aligns with one of the other key statements in the NICE IOG (2005), which states: *"Equitable access to services is a key issue. Many services have evolved over time and within geographical and other constraints, such as the availability of expertise and level of funding. These constraints remain real, but efforts must be made to minimise the variations in access. The overriding principle for the provision of services must be safe and effective services as locally as possible, not local services as safely as possible"*.

2.5 The role of the TYA MDaT

National policy (NICE Improving Outcomes Guidance 2005 and the national service specification for TYA cancer) require that all TYA patients (aged 16-24 years) are discussed both at a relevant SiSp diagnosis and treatment MDT and by the regional TYA MDT. This forms part of TYA Cancer Peer Review Measures/Quality Surveillance. The services provided by the TYA team differ from those provided by SiSp groups. The SiSp has primary responsibility for the investigation, diagnosis and treatment of cancer and every young person will be formally discussed at the relevant SiSp diagnostic MDT.

We call the TYA MDT the 'MDaT' both to avoid confusion between the two MDTs involved and to emphasise its role as an advisory body. The focus of the discussion at the MDaT is to ensure that each young persons needs are discussed holistically and that the advice and resources of the TYA service are offered to add value to the care each young person receives

The MDaT now also links with the development of the TYA IAM Portal (see section 10.1) so that YP can assess their needs and gain targeted support and information (Picture 1 & 2). Patients are encouraged to submit their assessment of their needs to the professionals caring for them, thus forming the structure around which the discussions that take place at the TYA MDaT are framed. The data generated from the IAM, and from the discussions at MDaT, can be captured within the IAM Portal system to provide information about how the service is meeting needs and where gaps exist.

Picture 1 and 2: A young person using the IAM Portal in partnership with a Teenage Cancer Trust CNS

3. STAFFING

Staffing for the TYA SW service consists of those who work at the PTC in Bristol and those who work at the six designated TYA hospitals across the region.

3.1 At the Principal Treatment Centre

Staff at the PTC represents both those in the core TYA team and those who have a key role in supporting the TYA MDaT (as defined in Peer Review Measures). Details are shown below.

Table 1: Details of staff with TYA responsibilities at the PTC

Role	Post holder at 31.12.16	Full/Part time (wte)	Funded by
TYA Core Team			
Lead Clinician	Dr Rachel Dommett	1.0wte (0.2wte specific to TYA)	NHS
Teenage Cancer Trust TYA Lead Nurse	Jamie Cargill	Band 8a 1.0wte	Teenage Cancer Trust
Clinical Psychologist	Dr Laura Baker[1]	Band 8a 1.0wte (0.4 wte TYA)	NHS
Clinical Psychologist	Dr Rachel Irwin[2]	Band 7 1.0 (0.4wte TYA)	NHS
Social Worker	Suzie Holmes	Band 7 1.0wte	CLIC Sargent
TYA Specialist Nurse	Jax Hulbert	Band 7 1.0wte	NHS
TYA Specialist Nurse	Claire Lewis-Norman[3]	Band 7 1.0wte	Teenage Cancer Trust
Youth Support Coordinator	Hannah Lind	Band 5 1.0wte	Teenage Cancer Trust
Regional TYA Service Coordinator and Project Manager	Rob Spate[4]	Band 5 1.0wte	Teenage Cancer Trust
MDaT coordinator	Megan Brock	Band 4 1.0wte (0.5wte TYA)	NHS
Clinicians with designated responsibilities to the TYA service			
Adult Haematology	Dr Caroline Furness	2 PA	NHS
Adult Sarcoma	Dr Adam Dangoor	0.5 PA	NHS
Adult CNS	Dr Jilly McLean	0.5 PA	NHS
Adult Germ Cell	Dr Anna Kuchel	0.5 PA	NHS
Paediatric Oncology	Dr Anthony NG	0.5 PA	NHS
Palliative Care	Dr Rachel McCoubrie[5]	No designated session in job plan	NHS

Non-core staff at PTC TYA service			
Music Therapist	Claire Fraser-Tytler	0.2wte	The Grand Appeal (Local charity)
Reiki Therapist	Claudia Bonney	0.4wte	The Sam Buxton Healing Trust
Reflexologist	Clare Greatorex	0.4wte	Teenage Cancer Trust and The Grand Appeal

Notes:

1. Dr Laura Baker has responsibilities to TYA and paediatric oncology and haematology services. Sue Dolby, Consultant Clinical Psychologist and Head of Psychological Health Services at UHB has oversight responsibilities for the psychological support offered to the TYA service. In addition, she receives funding from Macmillan (0.1 wte) to support a further contribution to TYA services on the IAM Portal Project.

2. UHB agreed to fund a new substantive 1.0 wte Band 7 Clinical Psychology post in BHOC. This post was 0.6 adult and 0.4 TYA provision. Dr Rachel Irwin was recruited to this post and commenced in January 2017.

3. Following a bid submitted to Teenager Cancer Trust for an additional 1.0wte Teenage Cancer Trust CNS, Claire Lewis-Norman was appointed in November 2016 and commenced her role in March 2017. Claire works alongside Jax Hulbert and they are able to outreach North Bristol NHS Trust and Royal United Hospitals Bath NHS Foundation Trust.

4. Hannah Pring was appointed in November 2016 but left the service in September 2017. Rob Spate joined the team in October 2017 having previously worked in the 100,000 genome project and Macmillan Living Well initiative team.

5. There is no designated session for TYA within adult palliative care, although there is intention to address this in 2018.

3.2 At Designated TYA Hospitals across the TYA SW Network

All the Teenage Cancer Trust CNSs at the designated hospitals are funded in partnership with the NHS and Teenage Cancer Trust.

A summary of the key roles involved in the delivery of TYA care at designated hospitals is shown in Table 2, below:

Table 2: Details of staff with TYA responsibilities at TYA designated hospitals

Role	**Post holder at 31.12.16**	**Full/Part time (wte)**	**Funded by**
Gloucestershire Hospitals NHS Foundation Trust			
Teenage Cancer Trust CNS	Megan Wilsher[1]	1.0wte	NHS & Cobalt[1] Teenage Cancer Trust Adopted
TYA Lead Clinician	Dr Asha Johny	No designated session in job plan[2]	NHS
Young Persons Social Worker	See note below[3]	-	CLIC Sargent
Royal United Hospital NHS Foundation Trust			
Teenage Cancer Trust CNS	Jax Hulbert / Claire Lewis-Norman	As part of role at PTC[4]	NHS/Teenage Cancer Trust
TYA Lead Clinician	Dr Sally Moore[2]	No designated session in job plan[2]	NHS
Taunton & Somerset NHS Foundation Trust			
Teenage Cancer Trust CNS	Nicola Neale[5]	1.0wte	Teenage Cancer Trust/NHS
TYA Lead Clinician	Dr Belinda Austin	No designated session in job plan[2]	NHS
Community Worker[6]	Daniel Honey	1.0wte	CLIC Sargent
Young Persons Social Worker	See note below[6]	-	CLIC Sargent
Royal Devon and Exeter NHS Foundation Trust			
Teenage Cancer Trust CNS	Lorraine Beddard	1.0wte	NHS/Teenage Cancer Trust
TYA Lead Clinician	Dr Peter Stephens	No designated session in job plan[2]	NHS
Community Worker[6]	Daniel Honey	1.0wte	CLIC Sargent
Young Persons Social Worker	Richard Nobes	1.0wte shared with Plymouth	CLIC Sargent
Plymouth Hospitals NHS Trust			
Teenage Cancer Trust CNS	Kerry McKay[7]	0.5wte	NHS
Teenage Cancer Trust CNS	Lucy Figg[7]	0.5wte	Teenage Cancer Trust
TYA Lead Clinician	Dr Hannah Hunter	No designated session in job plan[2]	NHS

Young Persons Social Worker	Richard Nobes	1.0wte shared with Exeter	CLIC Sargent
Royal Cornwall Hospitals NHS Trust			
Teenage Cancer Trust CNS	Hannah Heayn[8] Nicola Clapson[8]	0.5wte	NHS
TYA Lead Clinician	Dr Toby Talbot	No designated session in job plan[2]	NHS
Young Persons Social Worker	Richard Nobes	1.0 wte shared with Exeter	CLIC Sargent

Notes:

1. Megan Willsher has a full time post funded jointly and equally by the NHS and a local charity (Cobalt).

2. None of the clinical leads for TYA at the designated hospitals have a specific sessional commitment funded for this role. This has been discussed and noted at each of the individual hospitals TYA Steering groups.

3. There is no CLIC Sargent Young Persons social worker based in Gloucester. Support may be offered from Suzie Holmes who works as part of the PTC team in Bristol but equity in service access is not assured.

4. Prior to 2017 the workload at the PTC precluded Jax Hulbert's presence on site in Royal United Hospital NHS Foundation Trust & North Bristol NHS Trust on a routine basis. The successful bid submitted to Teenage Cancer Trust and consequent appointment of an additional CNS post (1.0wte) has addressed this deficit.

5. Following a bid submitted to Teenager Cancer Trust for an additional CNS, Nicola Neale was appointed and commenced her role in July 2017. Nicola is based in Taunton but covers Somerset including Yeovil District Hospital which is a non-designated TYA hospital. Prior to Nicola starting in her role, Lorraine Beddard covered Exeter and Taunton.

6. There is no CLIC Sargent young persons social worker based in Taunton. Support for patients in Somerset may be allocated to Suzie Holmes who works as part of the PTC team in Bristol, or to Lin Snell, the paediatric CLIC Sargent social worker allocated to Taunton, or to Richard Nobes, CLIC Sargent social worker in Exeter and Plymouth.

7. Following a bid submitted to Teenager Cancer Trust for an additional 0.5wte TYA specialist nurse, Lucy Figg was appointed and commenced her role in October 2017. Lucy works alongside Kerry McKay covering Plymouth and South Devon.

8. Hannah Heayn went on maternity leave in June 2017 with her post covered by Nicola Clapson. This post has been a band 6 since 2011 despite funding being

available from specialised commissioning for a band 7 post. It is anticipated that the post will be re-banded when Hannah returns from maternity leave.

4. CLINICAL ACTIVITY

Cancer registration data suggest that approximately 150 TYA patients are diagnosed each year across the SW. Over the last few years there has been a steady estimated increase in patients supported by the TYA service (2015=66%; 2016=87%) with the aim to reach 100% of TYAs diagnosed in the SW. However there was no accurate measure on how many TYAs have been referred to the service and accessed support. In 2017 we undertook an audit to determine what proportion of TYA aged between 16yrs and 24yrs diagnosed (new or relapsed) with cancer who had been 'reached' by the service. (see section 10.3).

The overall reach rate for last 6 months in 2017 = 96%

4.1 Diagnosis classification of patients discussed at TYA SW MDaT in 2017

192 patients were discussed at the MDaT in 2017. Of these, 149 were new to the MDaT, of whom 140 were newly diagnosed (i.e. 'new to cancer').

Table 3 details the diagnostic classification of the patients discussed by the MDaT using the Birch classification[1] for TYA cancer (Table 3).

Table 3: Diagnostic classification of new patients discussed by MDaT in 2017 using updated Birch classification

Birch classification analysis				
Group			***New to MDaT***	***New to Cancer***
1	**Leukaemia**		**No.**	**No.**
	1.1	Acute lymphoid leukaemia (ALL)	11	11
	1.2	Acute myeloid leukaemia (AML)	8	8
	1.3	Chronic myeloid leukaemia (CML)	3	3
2	**Lymphoma**			
	2.1	Non-Hodgkin lymphoma (NHL)	1	1
	2.1.1	Non-Hodgkin lymphoma, specified subtype	12	11
	2.2	Hodgkin's lymphoma (HL)	5	4
	2.2.1	Hodgkin lymphoma, specified subtype	14	13
	2.2.2	Hodgkin lymphoma, subtype not specified	12	12
3	**Central Nervous System tumours**			
	3.1.2	Other low grade astrocytoma	2	2
	3.2.2	Other specified glioma	1	1
	3.3	Ependymoma	1	1
	3.4.1	Medulloblastoma	1	1
	3.5.1	Craniopharyngioma	1	1
	3.5.3	Pineal tumours	1	1

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[1] Classification and incidence of cancers in adolescents and young adults in England 1979-1997. Birch et al. Br J Cancer 2002;87(11):1267-74.

	3.5.7	Other specified tumours	1	1
4	**Bone tumours**			
	4.1	Osteosarcoma	4	3
	4.3	Ewing's sarcoma	1	1
	4.3.1	Ewing sarcoma of bone	3	2
5	**Soft Tissue Sarcoma**			
	5.2	Rhabdomyosarcoma	2	2
	5.3.3	Synovial sarcoma	1	1
	5.3.4	Clear cell sarcoma	1	1
	5.3.7	Alveolar soft part sarcoma	2	2
	5.3.8	Miscellaneous specified STS	2	2
6	**Germ Cell**			
	6.1	Gonadal germ cell & trophoblastic neoplasms	14	13
	6.2	Germ cell & trophoblastic neoplasms of non-gonadal sites	2	1
7	**Melanoma and Skin Carcinoma**			
	7.1	Melanoma	13	13
	7.2	Skin carcinoma	2	2
8	**Carcinoma (excluding skin)**			
	8.1	Carcinoma of thyroid	3	3
	8.2	Other carcinoma of head and neck	1	1
	8.2.3	Carcinoma of nasal cavity middle ear sinuses larynx and other ill-defined sites in head and neck	1	1
	8.4	Carcinoma of breast	2	2
	8.5	Carcinoma of genito-urinary (GU) tract	2	2
	8.5.2	Carcinoma of Bladder	1	1
	8.5.3	Carcinoma of Ovary	3	3
	8.6.1	Carcinoma of colon & rectum	2	2
	8.6.5	Carcinoma of other and ill-defined sites in GI tract	1	1
	8.7.2	Other carcinomas NEC	1	1
9	**Miscellaneous specified neoplasms NEC**			
10	**Unspecified Malignant Neoplasms**		1	1
11	**Non malignant**			
	11.1.	Aplastic anaemia	1	1
	11.4	Fibromatosis	2	2
	11.10	Langerhans Cell Histiocytosis	3	2
	11.13	Myofibroblastic	1	1
	11.17	Non-malignant tumour	2	2
			149	**140**

Lymphoma (29%), leukaemia (16%), Carcinoma (12%) Germ Cell Tumours (10%), Sarcoma (bone and soft tissue) (10%), and Central Nervous System tumours (6%) represented the most frequent major diagnostic groups amongst those newly diagnosed.

Patients are referred to the TYA MDaT from a wide range of SiSp MDTs and many are also discussed by more than one MDT before the diagnosis is confirmed and the treatment plan is agreed. Table 4 shows the referring MDT for the new patients discussed at the MDaT in 2017.

The MDTs referring the largest number of patients were haematology, sarcoma, brain, skin and testicular.

Table 4: Referring MDT for all patients discussed by MDaT for the first time in 2017 (n=149)

Patient Diagnosis	All		New to cancer	
	No. Pts	%	No. Pts	%
Haematology	41	28	40	29
Paediatric	21	14	20	14
Unknown	21	14	16	11
Skin	13	9	13	9
Testicular	11	7	10	7
Gynaecology	9	6	9	6
Sarcoma	9	6	8	6
Central Nervous System /Neuro oncology	6	4	6	4
Head & Neck	5	3	5	4
Lymphoma	3	2	3	2
Urology	3	2	3	2
Colorectal	2	1	2	1
Germ Cell	2	1	2	1
Breast	1	1	1	1
Leukaemia	1	1	1	1
Neuroendocrine	1	1	1	1
	149		140	

4.2 Patient demographics & completeness of data logged at TYA SW MDaT

Table 5 details the demographic profile of the 149 patients discussed for the first time by the TYA MDaT in 2017 and also provides an assessment of the completeness of data collection.

Table 5: Details of new patients discussed by TYA MDaT

DATA ITEM	***No. of patients for whom data has been collected***	***% of patients for whom data has been collected***
Patients first discussed in 2017	**149**	**100**
Male	72	48
Female	77	52
Ethnicity	**149**	**100**
Mixed : White and Asian	1	1
Other Ethnic Group : Any other ethnic group	1	1
Other Ethnic Group : Chinese	2	1
White : (White) British	51	36
White : Any other white background	3	2
Not Known	21	15
Unrecorded	61	44
Age at first cancer diagnosis	**149**	**100**
0 – 15 years	16	11
16 – 18 years	34	23
19 – 24 years	98	66
≥ 25 years	1	1
Age at Referral to MDaT	**149**	**100**
0 – 15 years*	4	3
16 – 18 years	43	29
19 – 24 years	96	64
≥ 25 years	6	4
Cancer Pathway Point at 1st MDaT	**149**	**100**
New diagnosis	140	94
Recurrence	6	4
Other	3	2
Hospital centre registered from:	**149**	**100**
Bath	6	4
Bristol (UHB)	59	40
Bristol (NBT)	2	1
Exeter	25	17
Gloucester/Cheltenham	17	11
Plymouth	17	11
Taunton	8	5
Torbay	4	3
Truro	8	5
Yeovil	1	1
Other	2	1

Clinical Trial Entry	**149**	**100**
Yes	20	13
Non- Recruitment	96	64
Unknown	33	22
Reason given for non-recruitment?	**96**	**100**
Suitable trial not available	86	90
Patient eligible but trial not offered	3	3
Patient eligible but declined	2	2
Not eligible	5	5

Fertility preservation recorded	**149**	**100**
Treatment not expected to affect fertility	49	33
Achieved Male - Sperm Storage	33	22
Not Known	21	14
Insufficient time to achieve fertility preservation before treatment started	10	7
Patient declined	10	7
Other	5	3
Achieved Female - Oocyte Freezing	5	3
Attempt made but unsuccessful	4	3
Achieved Female - GnRH analogue	4	3
Achieved Female - Ovarian Tissue Freezing	4	3
Achieved Female - Fertilised Egg Freezing	3	2
Achieved Male - Other	1	1
Achieved Female - Oophoropexy	0	0
Achieved Female - Other	0	0

*Notes: * The age at referral changed during 2016 as detailed in section 2.1*

Data completeness has continued to improve, however the data suggests that the completeness of data collection in relation to reason for non-recruitment to a clinical trial and fertility preservation could be improved. With the introduction of IAM Portal SW Integrated Multi-disciplinary Management System (SWIMMS) data collection and completeness should continue to improve throughout 2017 and into 2018.

4.3 Data obtained from IAM assessments

The TYA service uses a holistic approach to understand the needs of patients following a diagnosis of cancer. We have developed the IAM as a TYA specific alternative to the Macmillan eHNA or other SiSp holistic needs assessments in order to better capture information important to the care and support of YP with cancer.

The IAM explores YP's needs in 10 domains. These domains have been identified by TYA as important and have an effect on their resilience and adaptation to cancer. Needs in each domain are assessed, if possible, by the YP themselves, with or without the support of a professional. Members of the TYA team, usually the local TYA Specialist Nurse, will explain the IAM to each newly diagnosed patient and provide them with an appropriate link to the IAM portal (a website offering the patient the ability to complete the IAM assessment and to access associated information and support). Each domain is scored on a three point scale (1-3 or green, amber & red) which indicates the level of concern and/or need for information and support expressed by the YP in each area.

All patients as part of the standard offer are encouraged to complete an IAM both at the start and end of treatment. Of the 140 YP new to cancer and discussed for the first time at MDaT, 125 (89%) had an IAM score recorded at diagnosis. Of those finishing treatment, all YP will receive an end of treatment IAM.

Figure 4 below illustrates that of the 125 IAMs completed at time of diagnosis 60% were completed independently by the YP or in partnership with a health care professional, with over 80% using the IAM twice or more (figure 5)

Figure 4

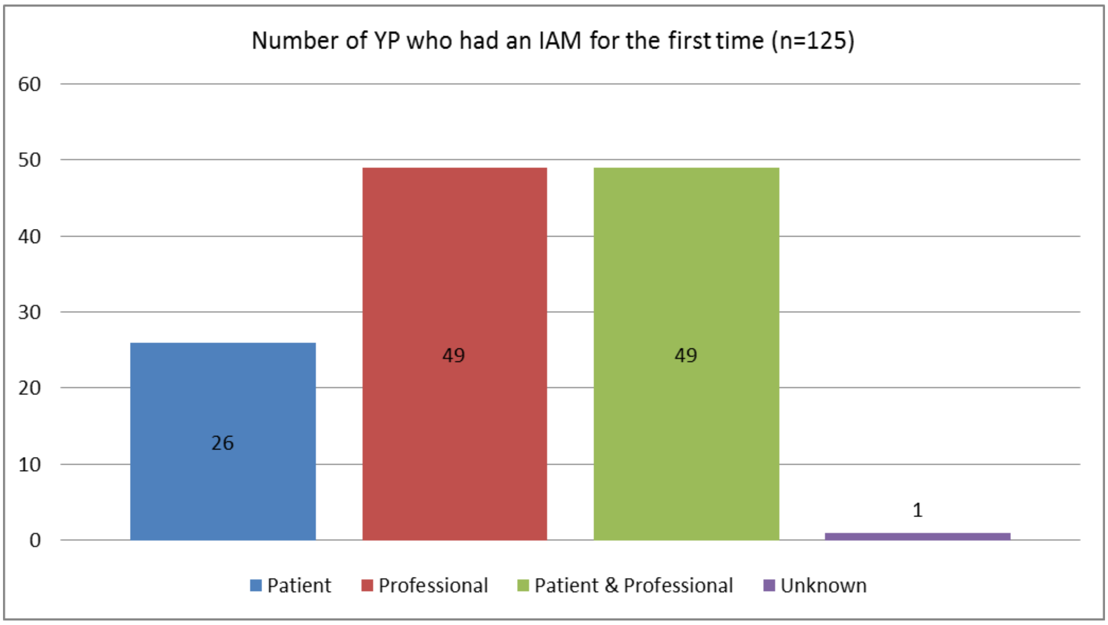
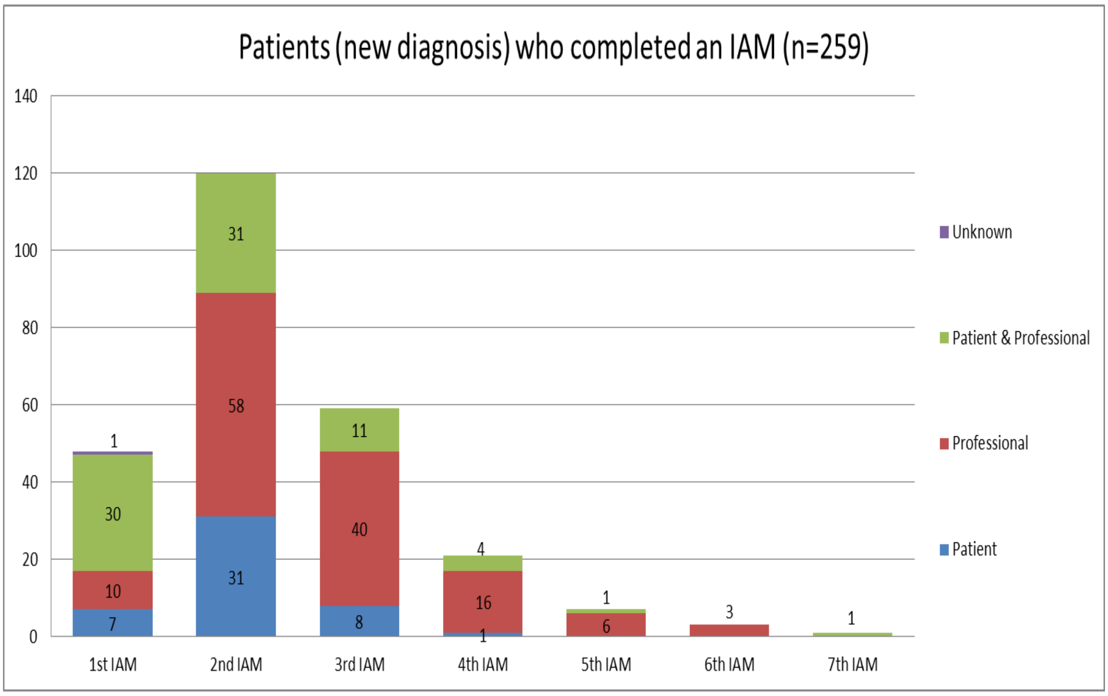


Figure 5



Overall 275 IAMs were completed in 2017 with 80% of all YP using the IAM twice or more. (Figure 6)

Figure 6

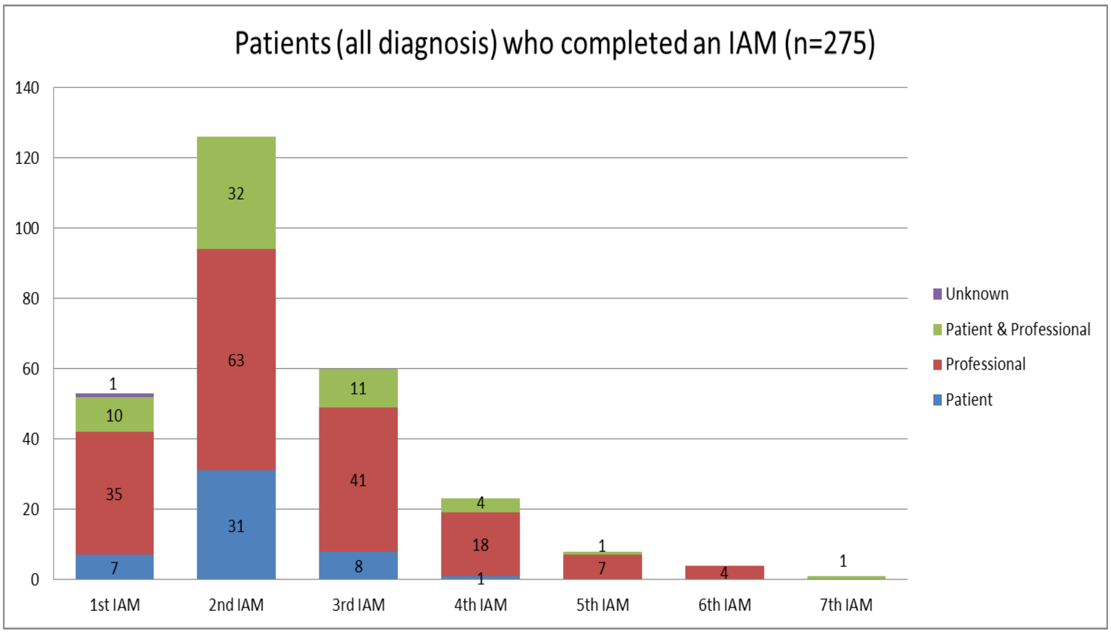
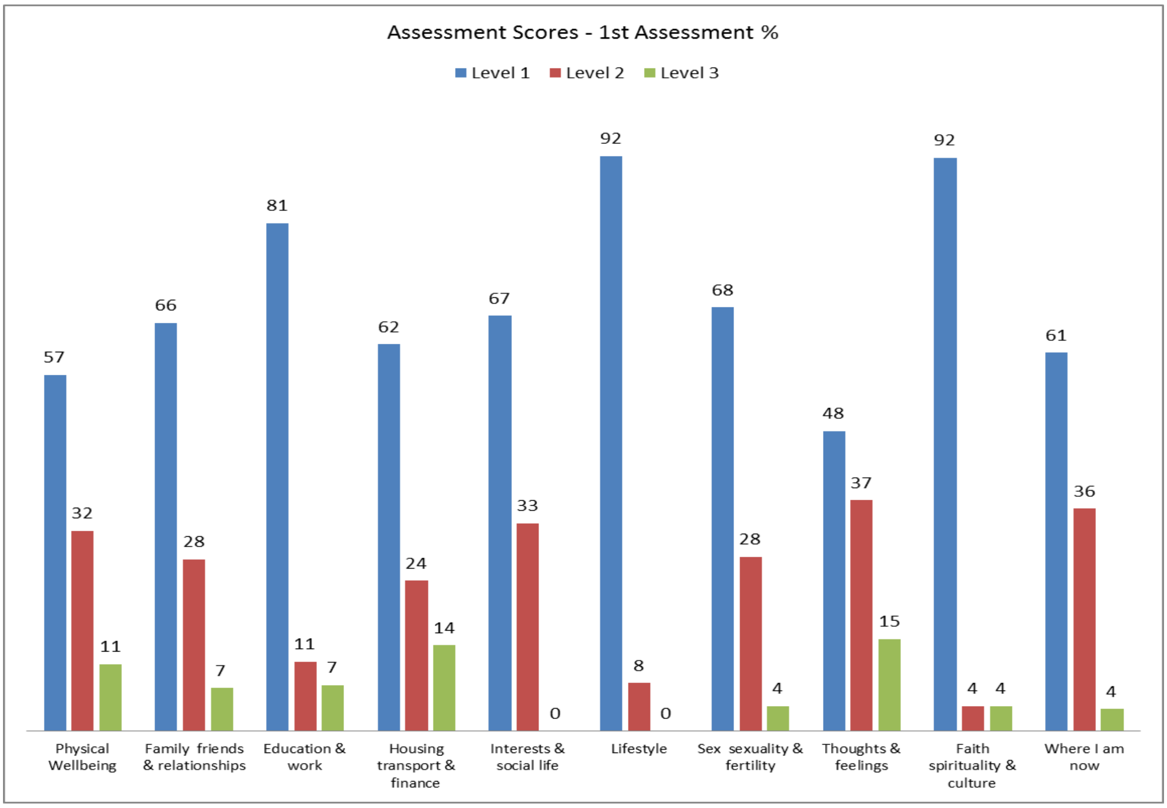


Table 6: Average scores in each domain at first MDaT IAM assessment (all patients discussed in 2017). The IAM is scored on a three point scale 1-3 where 1 indicates no additional need and 3 identifies significant additional need

Average Score by Assessment	**IAM Assessment 1**
Physical Wellbeing	1.5
Family, Friends & Relationships	1.4
Education and Work	1.3
Housing, Transport & Finance	1.5
Interests and Social Life	1.3
Lifestyle	1.0
Sex, Sexuality & Fertility	1.2
Thoughts & Feelings	1.6
Faith, Spirituality & Culture	1.0
Where I am now…	1.4

Figure 7. The distribution of IAM scores in each of the domains recorded at the first IAM assessment for all patients discussed by MDaT in 2017



The collection of data from IAM scores continues to increase; therefore it will become possible to undertake sub analyses by variables such as gender, diagnosis, age, cancer pathway point etc. Currently the highest level of need was identified in the thoughts and feelings domain with 35% scoring level 2 and 14% level 3. In education and work 40 % scored level 2 and 4% level 3.

4.4 Clinical Psychology Provision

During the period between January 2017 and December 2017, 69 referrals were accepted for specialist and targeted direct clinical work with TYA's and their networkers. 65 referrals were seen as outpatients with 205 follow-up appointments. The average number of follow up sessions was 3. (Table 7)

Eight YP were seen as inpatient referrals with 16 follow-up appointments, an average of two follow-up sessions. This data excludes some indirect patient-focussed work (e.g. time spent preparing therapeutic resources or preparing reports/referrals to other appropriate services). 66 appointments were not attended or cancelled.

Table 7

Referrals	Outpatients	Follow Up	Average Follow Up
69	65	205	3.2
Referrals	Inpatients	Follow Up	Average Follow Up
	8	16	2.0

Reasons for referrals included:

- emotional adaptation and adjustment to a cancer diagnosis and treatment
- procedural management
- concordance with treatment
- anxiety and depressed mood
- anger difficulties
- eating related difficulties
- behavioural difficulties related to treatment and its effects
- appearance related concerns
- trauma related difficulties
- managing the palliative care stage and immediate bereavement support

In addition to the above, a range of indirect services were offered to provide consultation, training and clinical supervision for non-specialist psychology staff to enhance the psychologically informed care provided by the TYA and SiSp MDT caring for TYA. This included attendance at the weekly TYA MDaT meeting, a monthly reflective practice for the TYA team and individual 1:1 clinical supervision of the TYA Reiki therapist and reflexologist. Additional psychological consultation and supervision regularly took place with other MDT members as required. Psychology Health Services (PHS) took a leading role in liaison with appropriate local and regional services (e.g. Mental Health Services and bereavement services) to ensure continuity of care and access to local services as needed.

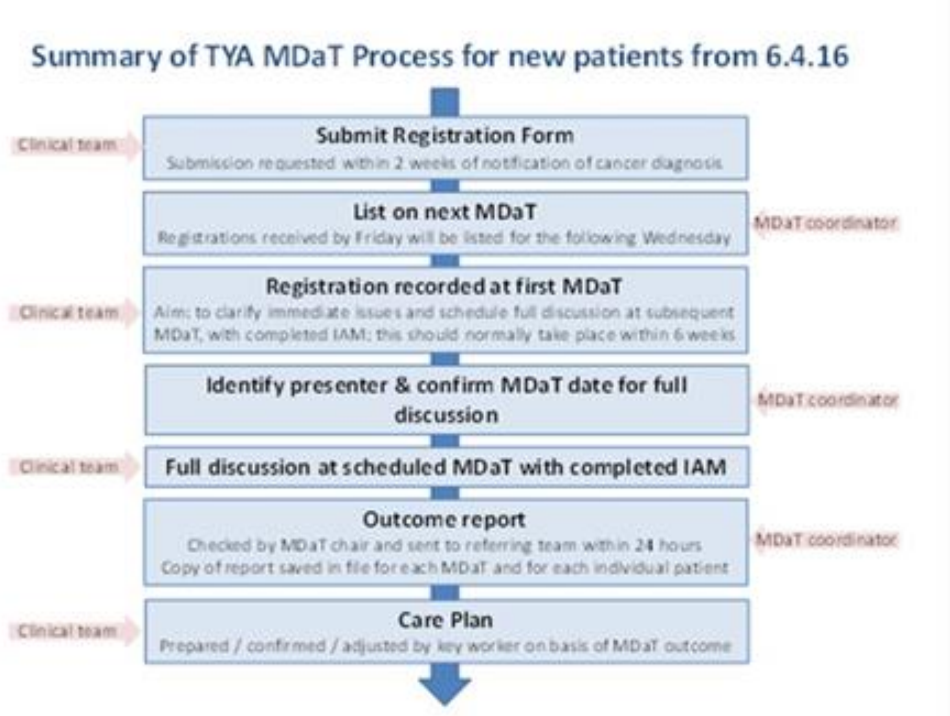
PHS led on planning and organising an away day for the SW TYA service, focusing on resilience, self-care and working together. A summary report was produced detailing the feedback, which was largely positive. PHS has set up a clinical supervision group for cancer support workers that include the Teenage Cancer Trust Youth Support Worker. PHS has had continued involvement in the development of the IAM Portal which includes access to supported self-management to build emotional resilience and psychological wellbeing. The PHS supported the TYA patient experience survey for both patients and networkers in line with quality surveillance.

Objectives for psychology provision in 2018-19 include continuing to contribute to service developments, research and audit. The Senior Clinical Psychologist will take over as co-chair of the national TYA psychology network. Additionally she will also offer two placements for a clinical psychologist in training and lead on the development of a TYA specific bereavement pathway for the Bristol service.

5. THE TYA MDaT

The TYA SW MDaT takes place as an online WebEx meeting and is held weekly on Wednesdays from 12:30-14:00. The referral of new patients is managed as a two-step process. Figure 8 summarises the process:

Figure 8



First, referrers are asked to register the patient by completing a registration form available on our website and emailing it to the MDaT Coordinator at UHB. The registration is listed at the next available MDaT so that the wider team are aware of the patient and to ensure that immediate needs are addressed. A date is suggested for a full discussion at a later meeting, usually within 4-6 weeks. The MDaT coordinator will then liaise with the referring team to obtain further information about the patient and to confirm the best date and time for them to join the MDaT for the full discussion about the patient.

At the full discussion, the chair of the MDaT (usually the TYA Lead Nurse or TYA Lead Clinician) facilitates a short presentation from the referring team around the patient's diagnosis, prognosis and treatment plan and will ask about recruitment to any available clinical trial and whether or not fertility preservation was necessary, possible or implemented. The patient's holistic needs are then discussed, using the IAM submitted prior to the meeting to structure the conversation. If the young person has not submitted their own IAM, or one done in partnership with a healthcare professional, the key worker is asked to submit a professionally led IAM before the MDaT discussion.

The outcomes and actions from the meeting should be used to inform the patient's care plan and are emailed (via nhs.net) to the referring team by the MDaT coordinator as a pdf document which can be downloaded to electronic medical records and/or printed and filed in the patient's notes. This includes a date for review at a future TYA MDaT if this has been agreed to be appropriate. All patients are routinely reviewed at/around the end of treatment.

For more information on the referral process and support offered by the TYA Cancer service please visit our website via SW TYA Cancer Service information for professionals

Table 8 & 9 shows the attendance by core and non-core members of the TYA MDaT at meetings held during 2017. Target attendance by individual core members of the TYA MDaT is 66%.

Table 8: Attendance by core and non-core members of the TYA MDaT

Attendance by core members of the TYA MDaT		% Meetings Attended	Dates in post if not for whole year
TYA Lead Clinician	Dr Rachel Dommett	84	
TYA Lead Nurse	Jamie Cargill	67	
Adult sarcoma MDT	Dr Dangoor/ Dr Ayre	4	
Adult germ cell MDT	Dr Kuchel/ Dr Braybrooke	22	
Adult Central Nervous System MDT	Dr Cameron/ Dr Maclean	40	
Adult haematology MDT	Dr Furness	58	
Paediatric Oncologist	Dr NG	67	
Clinical Psychologist	Dr Laura Baker or Dr Rachel Irwin	85	
Teenage Cancer Trust Specialist Nurse (Bristol & Bath)	Claire Lewis-Norman	71	
Teenage Cancer Trust Specialist Nurse (Bristol & Bath)	Jacqueline Hulbert	78	
CLIC Sargent Social Worker (Bristol)	Suzie Holmes (covered by Rachel Banks)	61	
Youth Support Coordinator	Hannah Lind	80	
TYA Wellbeing Co-ordinator SW TYA Cancer Service	Fran Hardman	37	Left June 2017
TYA MDaT Coordinator	Megan Brock (covered by Sandra Utylian)	100	

Table 9: Attendance by non-ore and non-core members of the TYA MDaT

Attendance of non-core members of the MDaT according to Peer review		% Meetings Attended	Dates in post if not for whole year
Teenage Cancer Trust Specialist Nurse (Plymouth)	Kerry McKay Lucy Figg	100	Commenced October 2017
Teenage Cancer Trust Specialist Nurse (Truro)	Hannah Heayn Nicola Clapson	76	Maternity leave from June 2017 Maternity cover from July 2017
Teenage Cancer Trust Specialist Nurse (Taunton)	Nicola Neale	74	Commenced July 2017
Teenage Cancer Trust Specialist Nurse (Gloucester)	Megan Wilsher	71	
Teenage Cancer Trust Specialist Nurse (Exeter)	Lorraine Beddard	76	
Social Work Team Leader SW	Rachel Banks	51	
CLIC Sargent Social Worker (Exeter/Plymouth/Cornwall)	Richard Nobes	49	

6. MANAGING THE NETWORK

A description of the service is provided in Section 2 of this report. Major points considered in discussions over the year about the integrity of the TYA SW network included:

- a recognition that the referral of all patients for discussion at the TYA MDaT was core to the management of the service
- endorsement of the original decision, taken in 2011, to commission the service as a network of care despite incomplete compliance with the expectations of the IOG with regard to place of treatment
- an acknowledgement of the challenges involved in ensuring that TYA patients were offered appropriate choice about place of treatment
- the need for reinvigoration of the role of the TYACNCG (TYA Cancer Network Coordinating Group), and a review of its membership.
- recognition of the following statement about the networking of care, published as an Appendix to the TYA Peer Review Measures, as a key value for the management of the TYA SW service:

  "They (rules for networking) allow the development of consistent, intra- and inter-team patient pathways which are clinically rational and in only the patients' best interests instead of in the vested interests of professional groups or of NHS statutory institutions".
- the need to review the existing age thresholds which define the TYA service, specifically in relation to the interface with paediatric services.

Despite illustrating this in 2016 the fact remains that none of the TYA lead clinicians at the designated hospitals have time adequately identified and available within their job plans to fulfil this role. Whilst the appointment of a network coordinator has supported some of the organisational issues involved in participation in the network, all clinical leads need more time to promote and engage with colleagues in their own hospitals over the issues relating to TYA care, and to develop local services. The place of the TYA steering groups held at designated hospitals have been reviewed and reinforced. These meetings serve to keep local hospital trust management informed as well as ensuring a regular interface between the TYA network lead and the TYA Lead Clinician and Lead Nurse.

During 2017 the Children and Young People's Cancer Clinical Reference Group (CYP CRG) have undertaken a systematic review of the national specification for the commissioning of cancer services with recommendations expected to be published summer 2018. The configuration of the network within the SW will need to consider these recommendations to ensure that the configuration and membership is fit for purpose. Until then the network will continue to meet with support provided by the two cancer alliances in the SW.

7. QUALITY SURVEILLANCE

7.1 Areas of non-compliance

A quality surveillance self-reporting exercise was undertaken in 2017. Table 10 details areas on non-compliance which have been identified in previous years and remain an issue.

Table 10

Non-compliant measure	**Update on action to address**
Other staffing (AHPs)	Currently a risk within the PTC. Business case submitted annually for investment for dedicated AHPs including physiotherapy, occupational therapy and dietetic support.
MDaT quorum	Despite clinicians representing their SiSp and being funded to attend the MDaT, attendance is not in line with recommendations. PTC cancer board and network are aware
MDaT attendance	As above

8. PATIENT EXPERIENCE

The annual patient and networker (defined as family, friends and others close to the patient) feedback questionnaires for 2017 were disseminated across the region at the beginning of February 2018 and remained open online until March 2018. The questionnaires were available in online and paper formats.

The Teenage Cancer Trust CNS and wider TYA team were crucial to maximising the response rates of these questionnaires and ensuring that feedback was received from across the SW. A full report is available on request.

8.1 TYA PATIENTS

48 responses were received from TYA (19.4% response rate) from across the region.

Responses were received from YP treated across the network including Bristol (33%), Exeter (23%) and Plymouth (23%)

94% of patients had heard of the TYA service and 92% had met a TYA team member.

Areas with particularly positive feedback were related to:

- information provided at transfer or transition of care
- support and information provided after treatment finished
- treatment options being clearly explained
- patients had an opportunity to ask questions
- staff explained their roles

and all patients

- felt listened to by TYA staff
- reported positive experience of the TYA service

80% reported an excellent experience and 98% of patients said overall the information they received was useful. The majority of patients (79%) reported that support continued after treatment had finished.

TYA's expressed that their cancer diagnosis had a high impact on their 'emotional wellbeing'. Responders also expressed increased difficulties in relation to

- physical wellbeing
- relationships
- general lifestyle
- interests and social life
- sex, sexuality and fertility

These findings are illustrated below in figures 9 & 10.

Figure 9

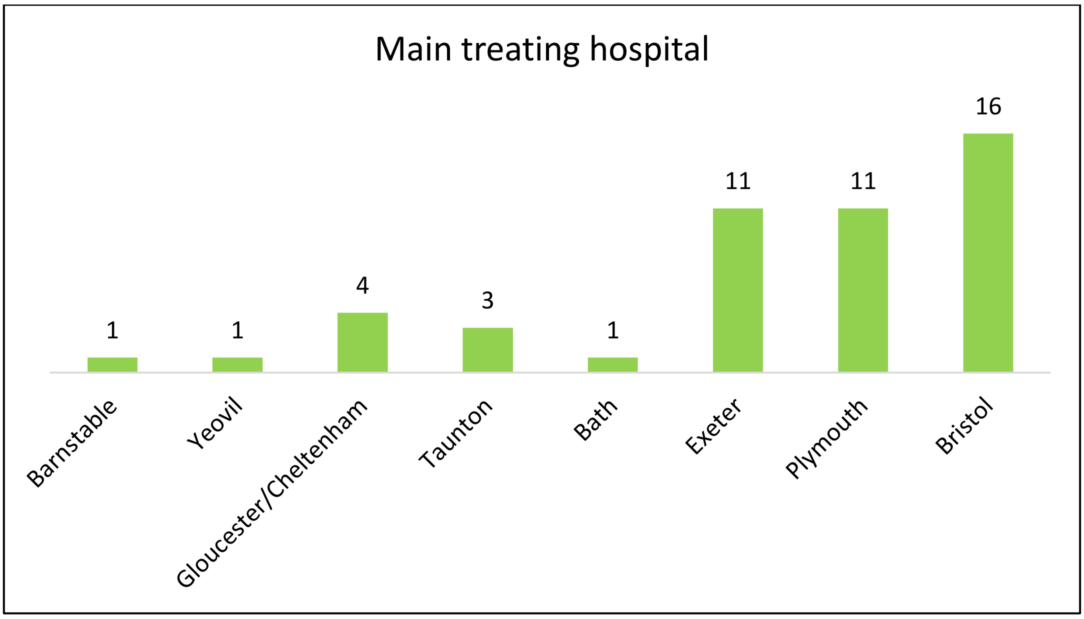
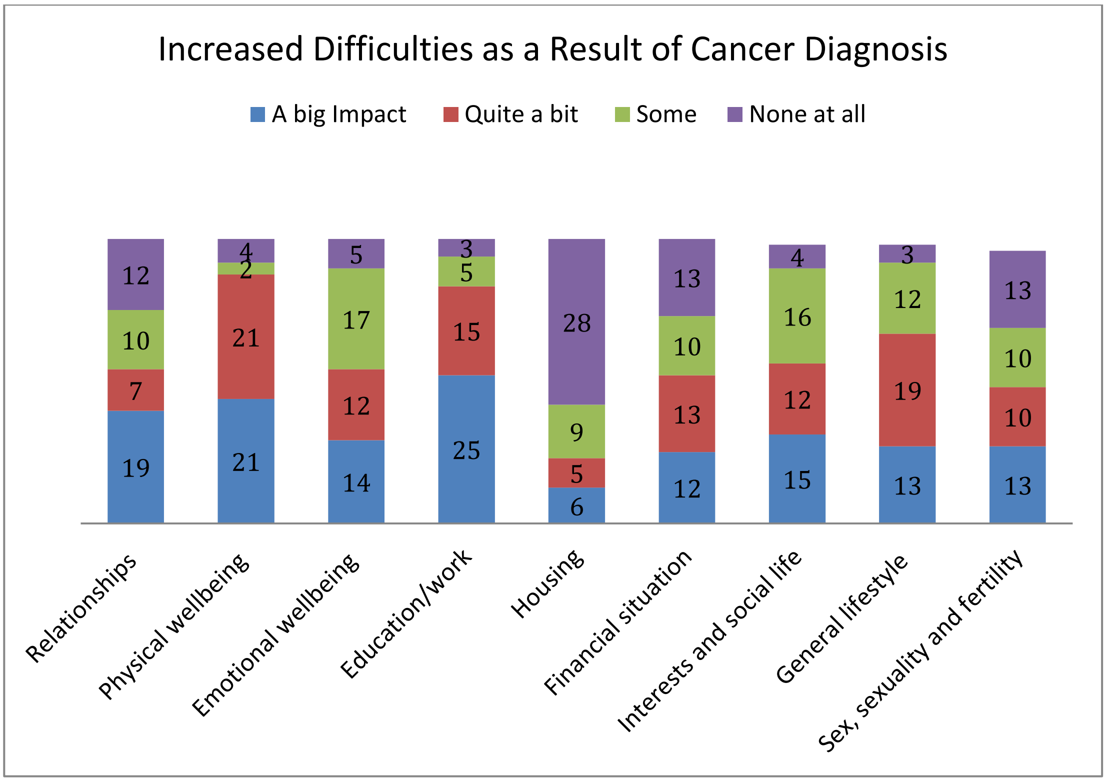


Figure 10 illustrates the level of impact as a result of the cancer diagnosis on various areas of life as rated by patients

Figure 10



Patients were also offered an opportunity to provide free text comments, the overwhelming majority of which were positive;

- *"The support I received was amazing, I couldn't have been happier"*
- *"TYA Team have been wonderful always ready to listen to me and answer any questions that I have"*
- *"The TYA Team really helped me, really impacted my treatment/hospital stays Amazing group of people"*

In summary areas for continued development in 2018 include: patients feeling listened to by all hospital staff, patients knowing who their keyworker is, continued development of the IAM portal to increase its helpfulness to patients, and supporting patients continued use of the IAM portal for self-management.

8.2 TYA NETWORKERS

27 'Networkers' also responded to a separate questionnaire which focused mainly on an assessment of their own needs rather than their views of the TYA service. 78% of networkers felt they received enough help in supporting their young person. This therefore remains an area of possible development for the service. The increase in psychology provision (0.4 wte), Reiki therapist (0.2 wte) and continued development of the Living Well programme for the supporters of TYA's, will hopefully help to address this. Networkers indicated that the main areas where help or support was needed were 'emotional support' and 'information about the illness'. 78% of networkers said they would prefer support from the TYA team members rather other health care professionals. These responses are illustrated below in Figure 11, & 12.

Figure 11 illustrates networkers felt they received enough help to support the young person

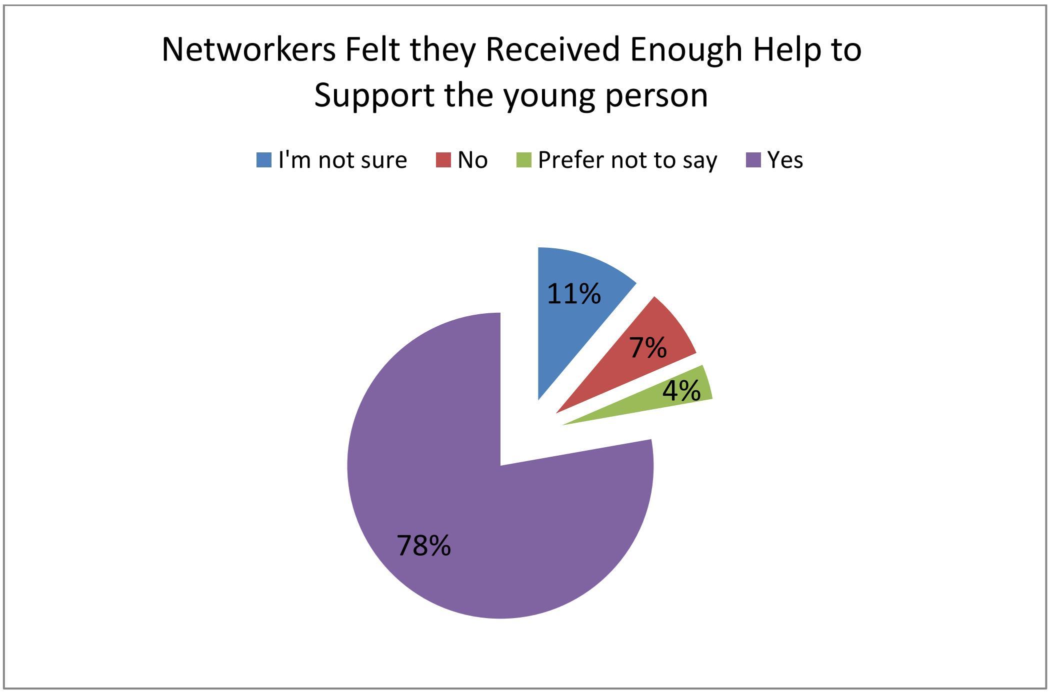
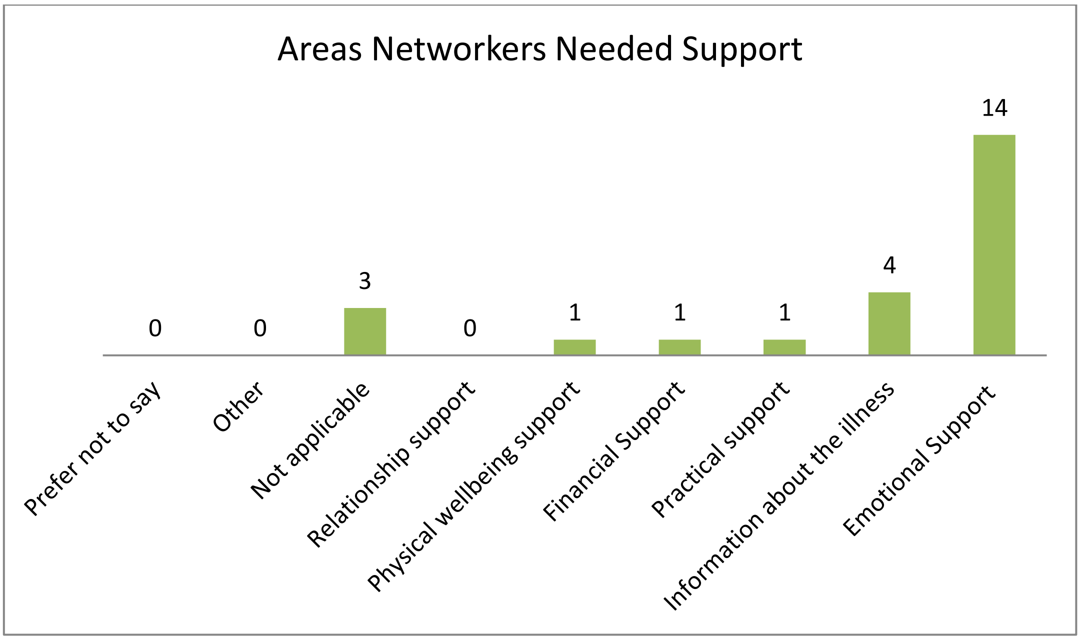


Figure 12 illustrates areas of help or support networkers required to support the young person.



Networkers were also offered an opportunity to provide free text comments, the overwhelming majority of which were positive;

- *"Exceptional, Outstanding, personalised. TYA Centred care"*
- *"I have found the TYA Service to be invaluable to me"*
- *"Amazing/Fabulous. Cannot thank the TYA Service enough for everything they do for my daughter"*
- *"TYA service at the hospital are wonderful. 100% supportive and excellent care".*

8.3 ACTIVITIES AND PEER SUPPORT

The Teenage Cancer Trust Youth Support Coordinator is responsible for a programme of activities within the PTC which offer TYA patients the opportunity for peer contact and support through social activities. Currently, around 100 YP are on her active contact list. She has met most of them, engages regularly with at least half and has a small number that she sees on a regular, daily (when in hospital) or weekly basis.

Planned group sessions happen 2-3 times a week with spontaneous sessions arranged depending on who is in the TYA unit. Regular activities include afternoon tea and music sessions (every week). Other regular group events are arranged quarterly, for example "Look good feel better" sessions and D.J Workshops; intermittent activities include art workshops and a monthly social/ peer support group which has included meals out, bowling, escape games and comedy gigs

"Our social evening at 'Stokes Croft china was a very fun, creative evening. Run by the people's republic of Stokes Croft, the ethos of the organisation is socialism and civil liberty. They are known for creating radical fine English bone china, so we all

made a beautiful piece to take away…. But definitely not a cuppa that you would give to your grandma!!!"

One to one sessions are organised on an 'as required' basis and usually arise if a young person needs specific advice or support around a particular aspect of their life, for example, discussions about job seeking or volunteering opportunities. One to one support is particularly useful for in patients who are bed bound or in isolation or when a young person doesn't have much support from friends or family.

This support is highly valued, as illustrated by these quotes from YP:

"*Without the events organised by the youth support coordinator I wouldn't be as confident as I am now, and having an amazing time too!"*

"She handles everything! From organising trips that help take your mind off of treatment, to popping in for a chat, making sure there are no problems, it's nice to know there's someone on your side. A positive and friendly face to keep everything upbeat, and she always seems like she knows what she's doing with regards to the more complex hospital rules and systems too."

"*Hannah has helped lots with the unfortunate circumstances I found myself in not that long ago. By organising so many events just to take our minds of the worst even for a couple of hours and she's a ray of sunshine which makes you feel like it can't be that bad*."

Each of the designated hospitals host similar activities facilitated by the Teenage Cancer Trust CNSs, CLIC Sargent colleagues and volunteers. This constitutes social activities that include evening meals, outdoor activities & music groups. An example of the success of these initiatives was when two social events occurred on the same evening in Plymouth and Exeter, with 40 YP attending in total. All events and social activities are funded and supported by Teenage Cancer Trust, CLIC Sargent and local charities. Peer support for YP out with the PTC will be formally evaluated in 2018.

YP across the SW attended the Teenage Cancer Trust FYSOT weekends (under and over 18yrs), Ellen MacArthur sailing trips, Royal Albert Hall gigs hosted by Teenage Cancer Trust & The Way Forward initiative.

9. EDUCATION & TRAINING

The TYA SW service has always prioritised the provision of training opportunities for staff involved in TYA care.

9.1 Study Days

"Strictly TYA"

In 2010, a learning needs analysis was conducted of all staff involved in the care of TYA within UHB. This resulted in the development of a multidisciplinary teaching course entitled 'Strictly TYA'. The aim of this study day is to explore the normal physical, psychological and social development of teenagers and young adults and appreciate the effect cancer has on these areas. The content includes the physical, psychological and ethical aspects of TYA care plus issues of policy, communication and transition.

Two 'Strictly TYA' study days were delivered in March and September in 2017. Overall 30 regionally based multi-professional delegates attended. As in 2016 feedback was extremely positive and all either agreed or strongly agreed that they had "learnt a lot from the study day" and all "would recommend to their colleagues".

> *"A brilliant and informative day. I rotate working with TYA and adults and sometimes find it hard to build relationships with TYA patients because of issues relating to their age. This day has helped me understand TYA patients and their expectations. Found it great that past/present TYA patients were here".*

9.2 Other teaching / training

Members of the team continue to contribute in the delivery of age specific training in a number of higher education institutions including Coventry University, Cardiff University, Plymouth University and University of the West of England (UWE).

9.3 Conference Presentations

In December 2017, three members of the Bristol TYA team and the IAM Portal programme attended the 2nd Global AYA Cancer Congress in Atlanta, USA giving four presentations on work done by the TYA SW Clinical Service. The abstract titles were:

- *The development of a two-day wellbeing course for supporters of adolescents and young Adults with cancer*; Joliffe R, Cargill J**,** Polley M, French H, Hardman F, Seers H, Baker L
- *The development and evaluation of a reflexology service for adolescents and young adults with cancer and their supporters*; Greatorex C & Cargill J
- *A co-designed feasibility pilot exploring Virtual Reality technology with adolescents and young adults with cancer and their supporters*; Manchester H, Hinder H, Lind H, Hardman, H, Ingram E, Cargill J.
- *IAM Portal; evaluating the impact of the IAM Portal, and assessing scalability in the East Midlands in the Teenage and Young Adult Cancer Service*; Cheshire, J, Cargill J, Poole J, Henning I, Ross E, Stevens M

Other conferences the team have contributed to included:

- UHBristol International Nurses day celebrations (May 2017)
- TYAC Conference (July 2017)
- TYACON 2017, 6th National Teenage and Young Adult Oncology Conference, Tata Memorial Centre, Mumbai, India (September 2017)

10. RESEARCH, SERVICE DEVELOPMENT AND AUDIT

10.1 RESEARCH

The TYA service has supported two studies as PI. This includes:

- *'Online information and support needs of YP with cancer: A participatory action research study'* – Sponsor UCLH Sarah Lea, Ana Martins, Sue Morgan, Jamie Cargill, Rachel M Taylor, Lorna A Fern
- *'An examination of the role of partners in helping to meet the support needs of adolescents and young adults with cancer'* – sponsor Cardiff university Jane Davies, Jenny Labaton Jamie Cargill, Danny Kelly

10.2 SERVICE DEVELOPMENT INITIATIVES

Strong leadership has been key to the implementation of a network approach of delivering TYA cancer care in the SW of England. Additionally developing a service with a strong emphasis on service development through quality innovation has been essential for success. Current service development initiatives are summarised in table 12

Table 12

Impact area: local, regional or national	**Description of service development / intervention / project**
Local, regional and national	Capital and revenue support from, and close collaboration with, Teenage Cancer Trust to further develop resources both at the Principal Treatment Centre and at designated hospitals within the TYA SW network
Local, Regional and National	IAM Portal project – a project developing an electronic holistic needs assessment (eHNA) for TYA patients - see section 10.2.1
Local and regional	Peer support – the Youth Support Coordinator, with other members of our team, has regular engagement with YP in a programme of activities that, although built around social events, is intended to foster peer support. Peer support out with the PTC is now established across 4 designated hospitals in the SW. A full review and evaluation will be undertaken in 2018.
Local and regional	Continued development of bespoke wellbeing initiatives such as The Way Forward and a complementary service – see section 10.2.2

Regional	Living Well Programme – Parents/Carers of TYA cancer patients – a project partnership between Penny Brohn www.pennybrohncancercare.org and the SW TYA team to develop and deliver a pilot 'Living Well' programme for parents or carers of TYA cancer patients from the SW region. **Full report available**
Regional	REACH Audit - In 2017 we undertook an audit to determine what proportion of YP aged between 16yrs and 24yrs diagnosed (new or relapsed) with cancer who have been 'reached' by the service - **The overall reach rate for 2017 overall is 166 of 176 patients known = 96.15%.** (see section 10.3)
Regional	Place of death audit - The TYA Cancer service identified Place of death as an area of improvement but lacked local data. The service under took an audit of the place of death of patients alongside scoping the accessibility and criteria to hospice care in the SW for TYAs aged 16-24yrs. (see section 10.3)
Regional	Mentorship programme with Macmillan and Princes Trust – **Full report available**

10.2.1 IAM PORTAL PROJECT

Work done by the TYA SW cancer service team developed the concept of an age specific, multi-domain framework for HNA which would provide a structure to ensure that all YP were offered assessment and that review discussions incorporated the impact of, and adjustment to, their cancer and its treatment within a bio-psycho-social-educational-vocational framework i.e. what does having this cancer and its treatment mean for YP and their support network at this point in time. Once implemented, work was further developed in partnership with the Macmillan funded TYA On Target Programme her at UH Bristol resulting in the development of the TYA specific IAM which has now been developed for access via a website (www.tyaiam.co.uk) and, this year an app for use on all mobile devices.

TYA Help website

Other work within the TYA OnTarget Programme led to the development of a website offering YP access to advice and information to support emotional and psychological wellbeing (www.tyahelp.co.uk). This derived from work with YP themselves who highlighted the lack of such resources and the value of access to age appropriate, cancer specific support of this kind. The resources have been broadened over the last year to incorporate the other domains of the IAM, and to increase the multi-media presentation of information.

TYA SW IAM Portal Project

The separate but parallel development of the TYA IAM and the TYA Help website was governed by the same key principles, particularly by the engagement of YP in a co-creation / co-design process in developing both solutions. In that context it became clear that the integration of holistic needs assessment with a resource for self-management would better meet the needs of YP. Furthermore, as the TYA IAM had also become the framework used to structure the discussion of YP's needs at the TYA MDaT meetings, the ability to capture IAM scores as an indicator of patient need was recognised as a valuable tool to influence service development. This led to the development of an MDaT management system and data base – TYA SWIMMS.

The integration of the TYA IAM with the TYA Help website, now expanded to include rich sources of information about all aspects of TYA cancer experience (much of it utilising material developed and presented by YP), and linked to SWIMMS now constitutes the TYA IAM Portal Project.

The 'package' offers:

TYA patients individual access to an age specific self-assessment tool through which they can explore and document their needs holistic *and* obtain information and support from an integrated framework of resources for self-management

TYA clinical teams: access to individual patient self-assessments (released only by patient permission) which can inform MDT and other discussions and from which individualised care plans can be formulated. Professionals also have access to the Portal for the same wide range of information and resources for use in the support of TYA and their families.

TYA services and provider Trusts: access to a database for managing MDT activity and documenting its discussions, and for reporting activity, analysing patient need and assessing service demand

The NHS and its Voluntary Sector Partners: access to reports of aggregated data from anonymised patient records providing a profile of TYA patients and their needs.

Ongoing

Collateral benefits of the development of the IAM Portal have been seen in the way that clinicians from many SiSp teams have been engaged across the network; 'normalising' the involvement of YP in service development; and reorienting MDaT discussions away from the traditional 'medical' model towards truly multidisciplinary/multi-professional discussions of each young persons wider holistic needs.

After further pilot experience in another regional TYA service (in the East Midlands), the model of care developed in the SW has been assured by an ongoing partnership with Teenage Cancer Trust and Macmillan Cancer Support with national dissemination of the IAM Portal as the preferred platform for TYA cancer care.

A short video explaining the IAM Portal and its benefits to patient care can be seen at: https://vimeo.com/191019826/82be6cdd49.

In November 2017, the team were awarded a Macmillan Professionals Excellence Award in Innovation Excellence for this work

10.2.2 WELLBEING – COMPLEMENTARY THERAPY

Following the success of the TYA Reflexology and Reiki Pilot we now provide complementary therapies to TYA patients and their supporters. .

The main purpose of the use of complementary therapy in this setting is to help:

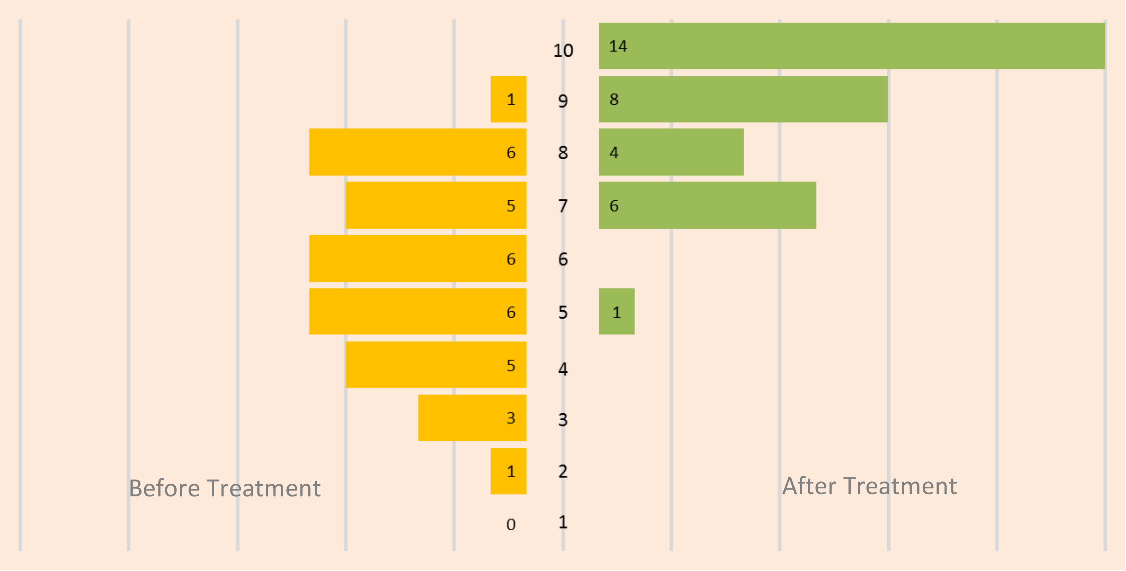
- promote relaxation
- reduce anxiety, stress and tension
- ease symptoms such as pain, nausea, poor sleep
- support the recipient find coping strategies and feel more in control
- improve quality of life.

Table 13 Reiki complementary therapy in 2017 (3 months data for paediatrics and TYA)

Patients sessions	Staff sessions	Supporter sessions	Offered but refused	Total sessions
106	40	88	2	236

Patients receiving more than one session	Carers receiving more than one session	Staff members receiving more than one session
23	17	5

Figure 14 Wellbeing BEFORE and AFTER treatment [Marks out of 10 (10 being excellent)] (n=33)



Feedback

''Excellent treatment that I will continue to use throughout my treatment and recovery' **Patient**

"The session exceeded my expectations I found it really helpful from a mental perspective to help me relax and de-stress and I look forward to each session' **Patient**

'Thank you so much for an above excellent few weeks of Reiki, I can honestly say the sessions and feelings of wellbeing afterwards were above my expectations. I will be forever grateful to Claudia's help on this journey, thank you so very much." ***Parent***

Table 14 Reflexology complementary therapy during 2017

	Patient Sessions	Supporter Sessions	Total
Number of participants	47	32	79
Number of treatments	194	57	251

47 patients received between 1 and 26 reflexology treatments, and 32 supporters received between 1 and 6 treatments.

For those individuals who were complaining of a specific symptom, a score between 1-10 was recorded for this at the beginning of the reflexology session, 0 being no symptom (i.e no pain) and 10 being the worst.

For several patients and supporters, the reflexology sessions had a significant impact on symptoms and/or side effects of treatment. Physical symptoms such as headaches and generalised pains around the body were reduced, feelings of nausea diminished and energy returned for a short while.(Figure 15)

Figure 15 Symptoms BEFORE and AFTER treatment

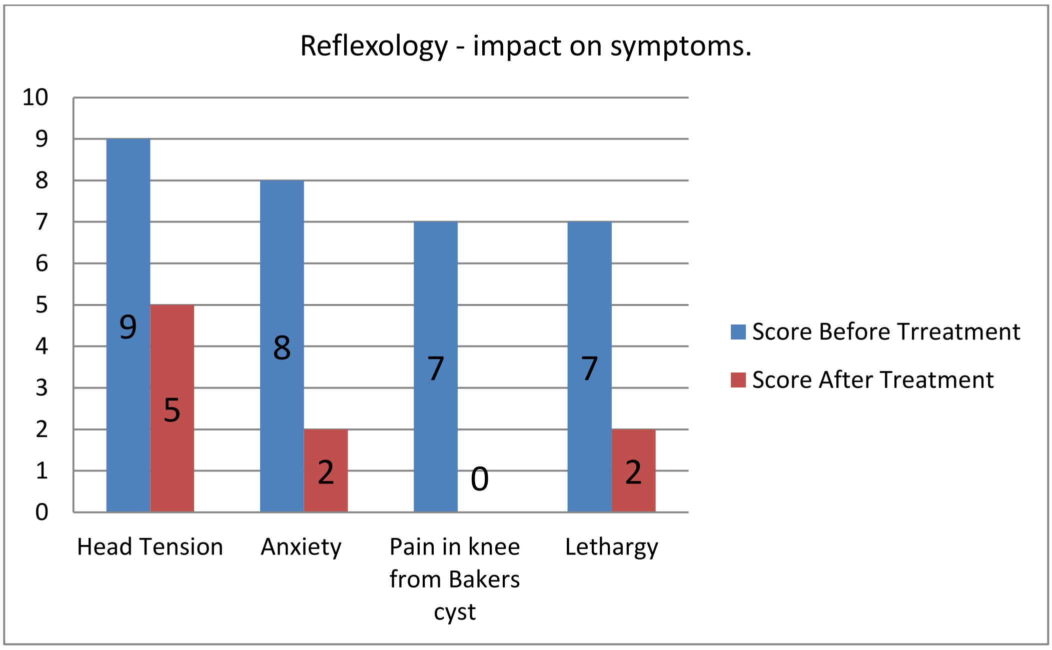
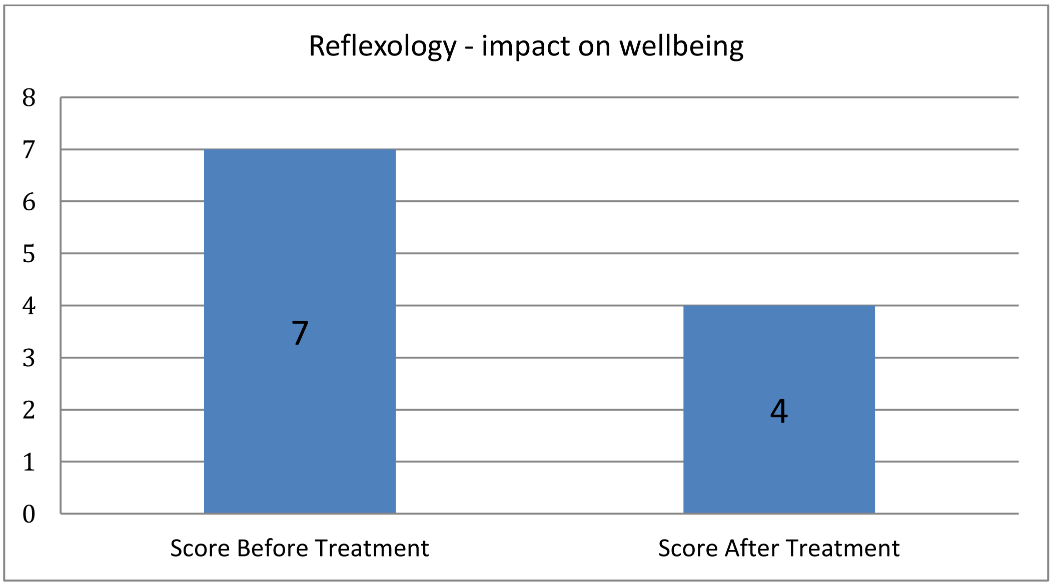


Figure 16 Wellbeing BEFORE and AFTER treatment



Wellbeing scores are rated with the higher number being the better score

10.3 AUDIT

1. “PLACE OF DEATH” INVESTIGATING PREFERRED PLACE OF DEATH AGAINST ACTUAL PLACE OF DEATH FOR TEENAGERS AND YOUNG ADULTS (TYA) IN THE SW OF ENGLAND

Introduction

Supporting TYA at end of life (EOL) is a fundamental part of TYA cancer care and includes understanding their wishes. As a TYA service there is a need to understand whether we are able to support these wishes. In this service evaluation we sought to understand whether TYA received EOL care in their preferred place of death (PoD) and explored hospice utilisation.

Method

Data was extracted on TYA aged 16-26yrs at date of death between March 2014-June 2018 using trust computer systems, cancer registries and regional databases. Demographic and diagnosis details were cross checked to ensure accuracy. Place of death, preferred place of death and if death was expected were recorded (if known).

Results

87 deaths were recorded; 76% were classified as expected. 36 TYA died in hospital, 31 at home, 12 in a hospice and 8 PoD unknown. Information on preferred and actual PoD was available for 55(63%) patients. 28 of the 37 patients who expressed a wish to die at home were able to do so, 8 died in hospital and 1 in a hospice. All patients who wanted to die in a hospice or hospital did so.

Discussion

In this evaluation 84% died in their preferred PoD. It is not always feasible to deliver EOL care outside of the hospital setting but it is important to understand reasons why. Early data was subject to recall bias but we have now been collecting prospective data since 2017 and this is ongoing in order to identify areas of unmet need and improve EOL services for TYA.

2. REACH AUDIT” ACHIEVING A SERVICE STANDARD OF REACHING 100% OF TEENAGERS AND YOUNG ADULTS (TYA) IN THE SW OF ENGLAND WHO HAVE RECEIVED A CANCER DIAGNOSIS

Introduction

TYA Cancer care in the SW is delivered in the Principal Treatment Centre (PTC) Bristol, 6 designated hospitals and infrequently in 4 non-designated hospitals in the region. There has been an increase in patients supported by the TYA service who aim to offer support to 100% of TYAs diagnosed. In 2017 the service undertook an audit to determine what proportion of TYAs aged 16-24 had been ‘reached’.

Method

An information request was sent to cancer managers to request all new registered cancer diagnoses during July–December 2017 in the PTC and 8 other Hospital Trusts. Data was cross-checked against the SWIMMS database and verified by the local teams. Any duplicates or non-cancer diagnoses were removed.

Results

In this period 58 TYAs with a cancer diagnosis were identified. Crosschecking against the SWIMMS database, 54 were registered with the TYA service. Of the 4 unregistered TYA, 2 were reached but declined support from the service and two referrals were missed. Median time from date of diagnosis to referral to TYA MDaT was 13 days (range 0-139). Overall reach rate 96%.

Discussion

The TYA SW service has seen a marked increase in referrals over the last few years; this audit demonstrates the validity of a regional service for TYAs and the pivotal role of the CNSs in the PTC and designated hospitals who outreach to non-designated trusts. There are still specific challenges for a timely referral that include information sharing, awareness of the service and appropriateness of offer.

11. BEST PRACTICE

There have been a number of significant areas of best practice from across the SW TYA Cancer service.

- REACH audit – **96.15%** of all patients diagnosed with cancer in the SW have been offered and supported by the TYA Cancer service in 2017 (5 years ago this was estimated 50%)
- The TYA IAM (IAM) Portal Project completed at the end of March 2017. Following the appointment of a national implementation manager the IAM Portal in April a roll out plan to implement across the UK by Teenage Cancer Trust is underway, in partnership with Macmillan Cancer Support, Sitekit and University Hospitals NHS Foundation Trust. The IAM Portal Project team won a Macmillan Innovation award for this work in November 2017.
- The TYA MDaT is still unique on how TYA MDT's are arranged and managed nationally. Following the successful pilot of the IAM Portal that includes SWIMMS, it is anticipated that the MDaT will be promoted as best practice for age appropriate MDT's with the IAM Portal the digital platform of choice for Teenage and Young Adult cancer services across the UK.
- The regional service has actively promoted peer and social activities for YP both at the PTC and equally in each of the designated hospitals. Such regular engagement with YP in a programme of activities built around social events promotes and fosters peer support.
- Reiki therapy and music therapy was added to the complementary offer available in Area 61 Teenage Cancer Trust Unit in Bristol. This provision is funded by Sam Buxton Healing Trust and The Grand Appeal and is available to children, teenagers, young adults and their networkers.
- The Teenage Cancer Trust CNS team were showcased by the Teenage Cancer Trust during the Royal Albert Hall Concerts in March 2017 – see Teenage Cancer Trust Nurse Specialists

12. OBJECTIVES FOR 2018

The overarching objective for 2018 is to consolidate and maintain the model of care evolved to date whilst maintaining a strong focus on innovation and service improvement.

Specific objectives include

1. Secure funding for;
    a. TYA Advanced Clinical Practitioner
    b. TYA CNS resource in Cornwall
    c. Regional peer support
    d. Complementary service in Bristol
    e. Improved facilities in Bristol supplementing Area 61 (Adult Oncology and adult BMT)
    f. Improve facilities in Gloucester and Cheltenham, Truro and Exeter hospitals
    g. Attendance of Palliative care consultant at TYA MDaT
2. Strengthen medical engagement in the network by ensuring that staff from the principal referring MDT's have time to engage with the TYA MDaT on a consistent basis.
3. Develop a strategy to incrementally improve access to clinical trials
4. Publish and disseminate findings from service improvement initiatives
5. Improve access to service activity and governance data
6. Illustrate and map out TYA pathways across the region (including supra-regional pathways)
7. Benchmark fertility preservation provision across in the SW
8. Map palliative/hospice care provision in the SW for TYA patients